People with intellectual and developmental disabilities (IDD) sometimes need help with everyday activities.

They might need help with things like:
- Personal care
- Getting dressed
- Making food
- Going to work

When people get help with these things, this is called long-term supports and services (LTSS).

Getting LTSS can be hard. Most people get LTSS paid for by Medicaid. Both the U.S. and state governments pay for Medicaid. But the governments do not give Medicaid LTSS to everyone. Getting Medicaid LTSS usually requires strict limits on how much a person can work and save.

It can be confusing to try and get Medicaid, so many people with disabilities don’t have it. They may have to wait a long time for LTSS, even if they need them. Lots of families of people with IDD do not get help from the government.

People with disabilities want to live in their communities. They do not want to live in institutions. But Medicaid makes it hard to get LTSS in the community.
Medicaid will give LTSS to people who qualify and live in an institution. But Medicaid will not always give people LTSS when they want to live in their own homes or in their community. People may have to wait to get LTSS in their community. Many people have to go on a waiting list.

The Arc talked with families of people with IDD. We found out that 1 in 4 families are stuck on waiting lists. Some people have been on waiting lists for 10 years. They are still waiting to get LTSS in their communities.

Some people in the government want to spend less money on Medicaid. In the past, they have tried to limit how much money the U.S. government can pay for Medicaid through block grants and caps.

Block grants or caps mean Medicaid would get less money. Less money means less Medicaid LTSS in the community and more waiting lists. The workers who help people with disabilities would be paid less. All these changes would make it harder for people to get the help they need.